

# Feeding Tube-Questions & Considerations for Healthcare Decision Makers:

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*This pamphlet will guide you as you make decisions about the possibility of getting a feeding tube. Our desire is to promote better communication between you, the team and your medical provider. We chose to use questions rather than providing “answers” because we think that there are many ways to answer each question. More importantly, we believe the questions should be based on your needs and your circumstances.*

You may be experiencing difficulty eating or drinking by mouth. How do you know if this is a problem and reason for concern? The following list of symptoms can help you understand if you have eating and drinking problems. People with eating or drinking difficulty frequently experience a combination of these symptoms.

- Experience fatigue while eating?
- Cough or choke while eating?
- Have heart burn often?
- Find you are losing weight and you do not know why?
- Take more than one hour to finish your meal?
- Know if someone on your team told you that you have *dysphagia* (trouble with swallowing) or *aspiration* (food goes into your breathing pipe)?

If so, then, you can:

- Ask your medical provider if you need a swallowing study or other tests and referrals
- Ask for Speech Therapist consultation
- Ask for S.A.F.E. Clinic evaluation (you do not need a referral)

If you are told that you have Dysphagia, now what? The following are some questions to consider asking your team and physician:

1. If I cannot eat by mouth, how can I eat? What are my options?
2. What are feeding tubes?
3. What are the different types of tubes and which one is best for me?
4. Does it hurt to have a feeding tube?
5. Can I eat or drink anything safely?
6. How can I get enough nutrition and fluids if I am not eating or drinking by mouth?
7. If I get a feeding tube can I ever drink or eat again?

8. Will I have a feeding tube forever?
9. What will happen if I decide (or my guardian decides) I should not have a feeding tube?
10. How will a tube change my day-to-day life?
11. Do I need to have the tube placed right now or can I wait?
12. Will the feeding tube prevent me from aspirating?
13. How will I take my medicines?
14. How will they put the tube in? Explain to me the surgery.
15. What could go wrong in the surgery? After?
16. What are the risks of having a feeding tube? Immediately and in the long run?
17. How soon after the surgery can I start receiving food and medicines through the tube?
18. Will I be able to go back to my home and what support will I need?
19. How do I take care of the tube at home? Does it need to be cleaned and how often?
20. How will I know if something is wrong with the feeding tube?
21. Can the feeding tube get wet: and can I bathe; or can I go swimming?
22. I live in a group home. Do I need more nursing if I have a feeding tube and what can the nurse do?
23. And can staff do any of the same things as the nurse?
24. What if the feeding tube comes out, who puts it right back in or do I have to go to the hospital for this?
25. When do I need follow up? And will I always need to see a specialist?
26. Does the tube need to be replaced? How often?
27. Will I still have to brush my teeth? How will my oral hygiene change?
28. What if I can't tolerate the tube or the feedings? Then what?
29. How has having a feeding tube made others feel?
30. Given my medical condition, will having a feeding tube prolong my life?

If you or your team or your physician needs assistance with these questions you can contact:

- **Supports and Assessment for Feeding and Eating (S.A.F.E.) (505)272-0285**
- **Feeding Clinic at Carrie Tingley Hospital if younger than 22 years old (505)272-4311**
- **Continuum of Care Project (505)925-2350**
- **Clinical Services Bureau (505)841-2907**
- **NM DOH DDSD Regional Office Nurses:**
  - **Metro: 800-283-5548**
  - **NE: 866-315-7123**
  - **NW: 866-862-0048**
  - **SE: 866-895-9138**
  - **SW: 866-742-5226**